

Children's Special Health Services (CSHS) Medical Advisory Council Meeting

**Comfort Inn – Meeting Room E
Saturday – May 4, 2013
8:30 a.m. to 12:00 noon CDT**

Present from the Children's Special Health Services Division (CSHS), North Dakota Department of Health (DoH): Tamara Gallup-Millner, Division Director; Devaiah Muccatira, SSDI Program Coordinator; Tammie Johnson, Program Administrator; Candace Frohlich, Claims Processing Specialist; Diane Bruley, Administrative Assistant; Kim Hrubby, Program Administrator; and Brittany Getz, Administrative Assistant.

Present as Appointed Medical Advisory Council Members: Thomas Carver, DO; Joanne Luger, DDS; Marcus Fiechtner, MD; Blake Feil, DDS; Lea Floberg, NP; Jacqueline Quisno, MD; Myra Quanrud, MD; and John Martsolf, MD.

Present as Continuous Representation on the CSHS Medical Advisory Council: John Baird, MD, Special Populations Section Chief, DoH; Gary Betting, MD, Medical Services Division Medical Consultant, DHS; Laura Roberts, Family Advisory Council Designee; and Joan Connell, MD, CSHS Medical Director.

WELCOME AND INTRODUCTIONS

Tamara Gallup-Millner gave a warm welcome and thanked the Medical Advisory Council members for their assistance during the past year. Introductions were made and the agenda reviewed.

OPENING REMARKS

Dr. John Baird, the Special Populations Section Chief, welcomed the Medical Advisory Council as Dr. Terry Dwelle, the State Health Officer, was unable to attend. Dr. Baird relayed that the Legislative session just ended and there were a number of things that will affect the Health Department. Challenges include uncertain federal funding and the impact of the Affordable Care Act on CSHS. Dr. Baird thanked everyone for participating in the meeting.

CSHS DIVISION OVERVIEW AND UPDATE

Tamara Gallup-Millner relayed that CSHS functions with eight full-time staff and the part-time services of Dr. Joan Connell, CSHS Medical Director. Candace Frohlich who was unable to attend last year's meeting, and Tammie Johnson who came on board March 2013 were introduced. Tammy relayed that the CSHS Division's budget for the 2013-2015 biennium, which includes a combination of federal and state matching funds, is about \$3.0 million. It includes spending authority for federal funds and required matching funds. This session, the Legislature did not make any changes to the Executive (Governor's) budget that directly affects CSHS. CSHS submitted two optional budget requests, which unfortunately, were not included in the Governor's budget. One was funding to support the Early Hearing Detection and Intervention (EHDI) program and the other was funding to update the CSHS Client Server application, which was developed in 1999 and is now 14 years old. Dr. Carver asked how much money was requested for EHDI through the optional budget request. Kim relayed she thought it was approximately \$300,000.

The major federal funding source for the division continues to be the Title V MCH Block Grant, which has been flat funded for several years. Uncertainties with this federal funding source have been and will continue to be challenging. Some of the issues CSHS has experienced include a decrease in federal MCH block grant awards by nearly 11% over the last 10 years. This year, the impact of cuts due to sequestration is still being determined. The current SSDI grant was also reduced 27% from the previous award (\$91,045 to \$66,392, a decrease of \$24,653). It continues to be a challenge to address these types of funding shortfalls. Tammy relayed that she is taking a conservative approach until further information is available as it is likely that funding uncertainties will continue into the near future.

The CSHS Division has a two-fold mission: 1) To provide services for children with special health care needs and their families, and 2) To promote or develop health care systems that are family-centered, community-based, and coordinated.

Tammy shared some programmatic highlights and reviewed handouts that were included in the meeting packet. The main focus of the Medical Advisory Council meeting is to obtain advice for the Specialty Care Diagnostic and Treatment Program. This program helps families pay for medical services for eligible children. The Legislature mandated financial eligibility for the CSHS Treatment Program at 185% of the Federal Poverty Level. That equates to a family income of \$43,568, a year for a family of four. The only deduction allowed is annual health insurance premiums that are paid out-of-pocket. Families can receive services above the 185% level, but then share in a portion of the costs with CSHS.

Tammy reviewed the reports that were generated for the meeting. CSHS served about 2,200 children in FFY 2012. The number served this past year was slightly less than in FFY 2011. Overall, 92% of the children served by CSHS have a source of health care coverage. Frequently, CSHS is a secondary payer that fills the gaps for what other payers do not cover. Over the last few years, a trend of decreasing private insurance and increased Medicaid coverage has been noted for the children served through CSHS. Few changes are apparent in other coverage sources such as CHIP or IHS. Last year, CSHS paid out about \$190,000 in claims through MMIS. The billed amount and what insurance and CSHS paid is lower than the previous year. Claims for the cardiac and Russell Silver Syndrome programs are similar for the two years. CSHS payments through the Diagnostic and Treatment Program by condition ranged from a low of \$0 to a high of \$39,533. 86% of the Diagnostic and Treatment program claims were paid for the following seven conditions: diabetes (30%), handicapping malocclusion (21%), cleft lip/palate (16%), seizure disorder (6%), hearing loss (5%), acquired brain injury (4%), and asthma (4%). Dr. Baird asked about the claims payment report and that the majority of those conditions have no children being served in the past year. Tammy relayed that there are over 100 conditions on the medical condition list but CSHS does not always serve children with all of those conditions. Dr. Baird asked about the claims payment report and the columns titled total number of children served by CSHS and total number of children receiving claims payment. Tammy relayed that CSHS serves some children through clinics rather than paying for their claims. A lot of people think that if you have insurance all needs are met, but sometimes families have high cost things and there still needs to be gap filling. Dr. Martsof asked about the claims payment report and the column titled write off and if it is the insurance company writing it off. Tammy relayed that it is the provider who writes it off. Tammy relayed that CSHS sometimes serve families that are above the 185% of poverty and so the families have to pay a certain amount before CSHS will pay.

System of Care for Children with Special Health Care Needs

The Power of Prevention for Mothers and Children

Tammy briefly discussed the *Power of Prevention for Mothers and Children* handout. It highlights outcomes in MCH such as cost savings and enhancing quality of life.

Health Care Reform

Tammy discussed health care reform. She referred to the *Patient Protection and Affordable Care Act* handout. This document addresses the full impact of the Affordable Care Act and some of the promise that might be seen for the MCH population (e.g., home visiting, prevention focus, covered benefits, etc.). One of the big areas to be aware of are the consumer assistance programs that will help families navigate. There are some family organizations that are considering applying for grants to help families with that navigation piece. Some of the other things that have been concerning are the essential health benefits. One of the issues is the definition or lack thereof for habilitative services. It could make a big difference for the population that CSHS serves.

Needs Assessment

Data from the 2010/2011 National Health Survey of Children's Health was included in the packet. Tammy relayed that the survey allows CSHS to monitor some key indicators for children. This survey comes out every four years and it provides state-by-state data. The survey shows ND still has some struggles and challenges in areas like overweight, insurance, screening, and smoking within the household.

LEGISLATIVE UPDATE

Tammy gave a brief overview of some of the legislative bills that CSHS has been following this legislative session.

Departmental Budgets-

- **SB 2004** – Department of Health budget, which includes the Children's Special Health Services Division and a variety of other public health programs.
- **HB 1012** – Department of Human Services budget, which includes funding for various programs including those for low-income individuals and people with disabilities.

Autism Spectrum Disorders (ASD)

It started with four bills, which eventually were consolidated into one comprehensive bill.

- **HB 1038** – Comprehensive ASD bill that provides an appropriation and FTE's for the following:
 - establishment of an ASD database with mandatory reporting by qualified professionals.
 - a voucher program pilot project for individuals below 200% of the FPL from age 3 to under age 18; up to \$12,500 per year to each enrolled individual is available to help pay the costs of eligible services; bill identifies which services can and cannot be covered through the voucher (e.g., applied behavioral analysis and TEACCH are excluded while assistive technology and respite care are included). The Legislature wanted it to be a pilot program and start it small.
 - an expanded ASD Medicaid waiver (17 more "slots" for individuals birth through age 7).
 - a Legislative Management study during the 2013-2014 interim focusing on ASD services.
 - a state autism coordinator to implement a resource and service center, develop an outreach plan, conduct regional meetings and a conference, and develop a protocol for use after screenings.
 - a training program for medical and behavior health providers, education staff, childcare providers, and parents.

Dr. Baird asked if there were two FTE's put into the budget and Tammy replied yes. One FTE will go to the Department of Health to develop the registry and the other one will go to the Department of Human Services for the coordinator position. Dr. Baird asked how much money was allocated for everything in the bill. Tammy relayed that the Department of Health's portion was about \$235,000. Dr. Quanrud asked with the waiver as the child ages out, will they then reopen the slot or does it stay shutdown. Tammy relayed that's why they increased the age limit was to try to make sure that the kids that are currently in don't age out. Tammy relayed that the Department of Human Services will be redoing the waiver. CSHS will probably have a role with the autism database. Dr. Quanrud asked if the diagnosis depends on a medical diagnosis or an educational diagnosis. Tammy relayed that the law is extremely detailed about this. They will use DSM-5, which is new. A physician exam is also included. Dr. Carver asked if the reporting will be from new diagnoses or retroactively for patients physicians are following now. Tammy relayed that she is hoping all individuals are reported.

Genetics

- **SB 2131**- Relates to licensing of genetic counselors by the ND Board of Medical Examiners. Among other requirements, applicants for licensure must have a Master of Science degree from a genetic counseling training program that is accredited by the ABGC or an ABGC-approved equivalent organization and approved by the board or have a Doctoral degree from a medical genetics training program that is accredited by the AMBG and approved by the board. ND has three genetic counselors.

Screening

- **SB 2172** – Requires pulse oximetry screening for Critical Congenital Heart Defects before discharge for newborns in a hospital with a birthing center. The Department of Health is responsible for notification to medical staff and facilities regarding this new screening requirement. Tammy relayed that the Department of Health was neutral, but did provide some feedback that having a systems approach would be best. The Legislature did not want to monetarily support that so the Department of Health's role in this is not like it is for other screenings. It will be just to notify hospitals about the screening mandate. We won't be doing any of the follow-up data collection or educational pieces. Dr. Carver asked if there would be a tracking system or any funding. Tammy relayed no, there is no tracking system or funding. There have been a couple of states that have had experience with it and a lot of the hospitals haven't found it too burdensome, but they have found that there needed to be a tracking system, educational efforts on the protocols to screen, and follow-up support with some of the pediatric echoes and other things that are needed. Dr. Carver relayed that many of the states where this is being done are smaller states with larger urban centers and so the pediatric cardiologist is ten blocks away not 250 miles away. Dr. Connell relayed that Family Voices had a nice handout expressing some of those concerns and who is going to pay for the ambulance bill and that sort of thing. Dr. Connell relayed that it was her understanding that Blue Cross Blue Shield was not going to guarantee that they would pay for the ambulance bill. Dr. Martsof asked if the whole protocol was required because that puts everyone under a lot of obligation. Tammy relayed that it is a screening mandate only. Tammy relayed that the Department of Health would try to make sure that some of the best practice protocols are available on the Health Department website. Dr. Baird asked if there are reporting requirements. Tammy replied no and so we won't know how it is going.

Health Care Coverage

- **HB 1362** – Medicaid expansion for individuals under age 65 with incomes up to 138% of the FPL. The program will be implemented either through private carriers or by utilizing the health insurance exchange. Benefits may be reduced or eliminated if federal participation decreases or is

eliminated. DHS estimates 20,500 to 32,000 individuals could enroll in ND Medicaid as a result of the expansion.

- **SB 2109** – Relates to eligibility determinations for the Children’s Health Insurance Program. Use of a modified adjusted gross income (MAGI) is required by the ACA. Income limits using MAGI methodologies will be equivalent to the net income limits used previously (160% FPL). It will make some changes for who is eligible for families.

Developmental Disabilities

- **HB 1378** - During the 2013-2014 interim, this bill requires DHS to identify the estimated cost to implement a Medicaid waiver or amend an existing Medicaid waiver, to provide coverage for children who have continued and substantial medical and support needs, but whom, at the age of three years, no longer qualify for services under the developmental disabilities waiver. DHS shall secure input from stakeholders, including families, providers, and advocates in preparing the estimate. Many kids at age three maybe were not eligible at that point for other Developmental Disability services so there was a movement to see if that could be changed. It was turned into a study, but there might be some action on that to look if there should be some eligibility changes.
- **SB 2375** – Legislative management shall consider studying of home and community-based services in the state, including the need to expand the Medicaid waiver. It affects the Developmental Disability population.

Mental Health

- **SB 2243**- Legislative management shall consider studying behavioral health needs of youth and adults during the 2013-14 interim.
- **SB 2306**- School districts shall provide at least two hours of professional development relating to youth suicide risk indicators, appropriate staff response, and referral sources. DPI and DoH are to collaborate in obtaining and disseminating information and training materials.

Oral Health

- **HB 1135** – Provides a \$100,000 appropriation to the Department of Health for a mobile dental care services grant to provide dental treatment, prevention, and education services to low-income and underserved children in areas of the sate with limited or unavailable dental services.

Health System

- **HB 1034** – Legislative management shall study health care reform options, including implementation of the federal ACA and state alternatives for state-based health care reform. The insurance commissioner, state department of health, and department of human services are to provide status reports.
- **HB 1211** – Provides \$400,000 to the Department of Commerce to provide dollar-for-dollar matching funds to assist in the recruitment, distribution, supply, quality, and efficiency of personnel providing health services in rural areas of the state.

Child Care

CSHS was tracking these bills because many families had access issues for childcare for children with special needs. It started off as one bill, but then various sections were moved into three bills

- **HB 1422** – Defines group child care and the staffing requirements for a maximum group size of children by age group and provides an appropriation to DHS for various child care programs. \$300,000 is included to fund early childhood services specialists.
- **SB 2018** – Among other things, includes a loan guarantee for child care facilities. \$400,000 is included for grants to support licensed early childhood services providers that care for children

with disabilities or developmental delays. The grants may be used for equipment, renovation of facilities used to provide the services, and staff.

- **SB 2244** – Legislative management shall consider studying the availability of and access to child care services in the state. Dr. Quanrud asked where it says that they shall consider, if that meant they were going to study. Tammy relayed no.
 - Dr. Connell relayed that at the last AAP meeting, the person that oversees the childcare legislation was sad to report that you can now have more children per childcare provider and you no longer have to have an outdoor experience for the kids in daycare.

BUSINESS

Minutes

Dr. Connell asked if there were any comments or questions regarding the 2012 minutes. Dr. Fiechtner moved to approve the 2012 meeting minutes. Dr. Martsof seconded the motion and all were in favor. Motion carried. The minutes were approved.

Provider Qualifications, Certification, and Enrollment

CSHS Provider Certification

Candace shared that 118 specialists were due for re-certification per the information in the database. Of these, ten specialists were not certified but have current licenses. These include five family practice physicians, three internists, one speech language pathologist, and one orthopedist. Five specialists were removed from the specialty list as their licenses were expired and they had relocated out-of-state or retired.

In 2013, a complete verification process of every specialist is being performed. Licenses and certifications are being checked in addition to locations of practice to ensure accuracy of the list.

Tammy relayed that the current policy requires board certification within five years. Tammy asked if there were any specialties where it takes more than five years. Dr. Fiechtner said that they could be eligible for a period of time and most specialties will give them three chances to become certified, but after that, they would have to go back to training. Tammy asked if the five years was appropriate. Dr. Fiechtner said he believed it was. Dr. Fiechtner said that some physicians say they are board eligible but they never were certified. Dr. Connell said she heard at the AAP meeting that particularly on the east coast, there are pediatricians and other specialties that are completing residency and thinking why certify, but are still having an active and busy practice. Dr. Fiechtner said that most hospitals won't accept noncertified people. Dr. Connell stated that maybe this was becoming more plausible since we have outpatient practitioner and hospitalists. Dr. Quisno said that insurance companies won't reimburse at the same rate if the physician is not certified.

Provider Qualifications

Kim shared that CSHS previously put into policy that primary care providers can be utilized to provide diagnostic evaluations relevant to eligible conditions until a diagnosis has been confirmed. Then they need to consult with specialists to provide treatment services. CSHS has not had difficulty with this policy. It seems to be flowing smoothly. Certifications are still required for physicians acting as primary care providers.

Advice on CSHS Provider-related Issues

Enrollment of psychiatric-related providers

Dr. Connell shared that while CSHS does not have any psychiatric diagnoses that are medically eligible conditions; CSHS does have quite a few patients who do have chronic diseases who need psychiatric and behavioral health services. CSHS would consider covering that under treatment services. Dr. Connell then asked the council who CSHS should reimburse for providing mental health services to our patients with chronic health diseases. Dr. Connell then referred to the handout *Mental Health Providers: Tips on Finding One*. Dr. Fiechtner stated that he didn't know how CSHS could include some and not the others. Dr. Connell then asked how they would feel about a clinical nurse specialist providing medication recommendations, etc. for a child who may be on lots of chronic medications. Dr. Quanrud stated that she recently came across a clinician whose credentials include chiropractic neurologist, chiropractic internist, and chiropractic allergist. Dr. Fiechtner stated that there are Doctors of Osteopathic Medicine getting certified at their own little hospital for certification and have nothing to do with the national boards or anything else. He also stated that more and more of the Doctors of Osteopathic Medicine are being trained at their own facilities not at the regular medical facilities. Dr. Fiechtner stated that in his specialty, they become certified by training at a hospital not at an academic center. Dr. Carver stated that not all residency programs are academic centers per say. Dr. Fiechtner stated that they are in his field. Dr. Connell then asked if the Doctors of Osteopathic Medicine take the otolaryngology boards to which Dr. Fiechtner replied no, they take their own boards. Dr. Martsolf asked if they have a residency program at a hospital, don't they have to go through approval by the residency board. Dr. Fiechtner said no, not in Doctor of Osteopathic Medicine. Dr. Carver said the osteopathic association has their own residency and some of them are combined with doctor of medicine residencies. Many of them are not. They have their own accreditation board just like the doctor of medicine boards.

Dr. Quanrud asked if in North Dakota psychiatric certified nurse specialists have to be supervised by a physician. Lea Floberg stated that she believes they are probably handled much the same as nurse practitioners where for prescriptive authority, they have to have a supervising physician. Dr. Martsolf stated he wasn't sure a certified nurse specialist can prescribe. They can bill separately, but he doesn't believe they can prescribe. Dr. Connell referred to the *What is a Clinical Nurse Specialist?* handout. In the handout, it states that they have to have more than a bachelor's degree. Lea Floberg stated they have a master's degree, but it's a different track than the nurse practitioner. Dr. Quanrud asked what services CSHS would pay for, would it be counseling or medications. Dr. Connell stated all of the above. Sometimes these children just need some behavioral therapy, but sometimes they need medications. Dr. Connell relayed that it is the medication component that makes her nervous, particularly for those children that have metabolic issues or children who are on many other medications because of possible drug interactions. Dr. Fiechtner asked if people who have prescriptive qualifications have hospital affiliation. Dr. Connell said not always. Dr. Carver asked who Dr. Connell refers her patients to now for counseling. He stated that he uses pretty much every type of provider that is on the list. Dr. Connell stated she uses child psychologists for cognitive behavioral therapy and child psychiatrists for situations where she believes they need medications. Dr. Carver stated there are children who live in communities where that is not available, but they do have counselors. He stated he would like to see those services paid for otherwise those counselors wouldn't see the patient. Dr. Connell stated that her potential concern in this patient population is the prescribing medications part. Dr. Quanrud stated CSHS could cover these folks for counseling and for prescription services and see how it shapes out. Dr. Connell asked who the folks should be for prescriptive authority. Dr. Carver stated that is mandated within the state. Dr. Connell stated it sounded like the council was leaning towards that if they have prescriptive authority within the state of

North Dakota; we are OK with them prescribing medications. Dr. Connell stated CSHS would get back to the council if clinical nurse specialists do have prescriptive authority. Dr. Connell stated she would like to know more about what the clinical nurse specialist educational process is so roles of various providers can be better delineated.

Specialty nurse practitioners and physician assistants (PA) - are we ok covering services by them?

Dr. Quanrud asked if a PA would do an initial assessment or is it more of the follow-up. Dr. Quanrud stated that in Grand Forks, the PA's are doing the casting and the cast follow-up, but they are not assessing the need for surgery. Kim stated that the issue is that patients see the specialist and then all of the follow-up appointments are usually done with the nurse practitioner (NP) or PA because the specialists are overwhelmed. Kim then asked if CSHS should pay the claim because that's who the family is able to see or should CSHS not pay because the NP or PA are not the specialist by our definition. Dr. Betting stated that patients don't need prior authorization to see a PA or NP. If they are authorized providers and they submit a bill for something, there is no oversight every time about if the patient was approved to see that person. Dr. Betting stated that from his perspective if they have seen the appropriate specialist that recommended a course of treatment and they are following that then that should be paid for. Lea Floberg stated they don't practice independently when they are working within those specialties and the patient is seen initially by the doctor of medicine. Many of the mid-levels, especially at The Bone and Joint Center, work directly with one of the doctors of medicine so they are trained in what that doctor of medicine's practice will be, how they want them to handle things, and will do the follow-up. They follow the doctor of medicine's initially set plan of care and follow-up with the patients.

Dr. Connell mentioned the example that was brought up at the last Medical Advisory meeting of the family practitioner who worked in the orthopedic's clinic in Minot and the patient had an acute injury and showed up at the clinic. He was seen by the family practitioner for an orthopedic shoe. She believes that CSHS decided to pay for it because the family practitioner was considered competent by the orthopedics clinic. Dr. Connell stated that she was hearing that the council would like the initial visit done by the specialist, but follow-up care is ok by the NP or PA. If it doesn't occur in that order, then CSHS would have to review it on a case-by-case situation. Kim asked if CSHS should enroll them as specialists or should CSHS stick to the policy of needing a recommendation from their supervising specialist saying what they can and cannot treat. Dr. Carver stated that PA's are under someone's umbrella all the time, but NP's are not. They can be independent practitioners. Lea stated that NP's have to have a supervising physician in order to have prescriptive authority. Dr. Connell stated that CSHS is covering its bases by being consistent with what we are doing and it sounds like that is what the council would like.

Newborn Screening

Newborn Bloodspot Screening Program statistics

Tammy shared that CSHS has more of a role in long-term follow-up services to those individuals that are identified through newborn screening. Included in the meeting packet was 2011 ND newborn screening statistics. A variety of disorders continue to be identified.

Potential Screening

The Secretary's advisory committee on heritable disorders in newborns and children has recommended that severe combined immune deficiency (SCID) be included in newborn screening programs. This became a national standard in 2010 so ND is now exploring this addition to the newborn screening panel. SCID has not moved forward very far in ND. The Iowa group is piloting the addition of this condition. ND is taking a conservative route until we see how it pans out in Iowa. Critical Congenital

Heart Disease has moved forward. MPS 1 is still out there as a maybe and they are relooking at Pompe disease. The group that is making the recommendations for this area is the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. The group might be at risk because of the grant funding that supported it. We get the list of recommendations and go through a process in ND with our partners and decision makers whether or not we should move forward with it in the ND Department of Health. Tammy shared that whatever is covered as a screen, CSHS tries to cover it an eligible medical condition. Dr. Martsof asked if CSHS covers ambulance rides. Tammy replied that CSHS does not cover transportation.

Kim shared that CSHS recently implemented a new in-office procedure in coordination with the Iowa State Lab, which will assist us in providing outreach to families of babies with an abnormal newborn screening result. During this new outreach process, the program administrator informs the family of our Diagnostic and Treatment Program and answers any other care coordination questions the family may have. Three days after a positive screening result, staff call the family to offer support and service information. We chose the three day window so the physician has time to talk to the family so they aren't caught off guard. Typically, we discuss services such as the CSHS Diagnostic/Treatment Program, Early Intervention, and Right Track just to name a few. A few of the families have applied for CSHS services. It has been going well. Tammy asked if three days was reasonable because CSHS does not want to be the informers. Dr. Quanrud and Dr. Carver stated more time is needed, at least five to seven days.

Critical Congenital Heart Disease

Tammy shared the Critical Congenital Heart Disease bill. It is a reporting mandate, but there is no follow-up process. Dr. Carver stated that most of the birthing hospitals have been doing it already for awhile. Tammy stated the Department of Health did a survey of some of the hospitals. They found that it's not uniform. Dr. Betting asked why they put in the language about not doing the pulse oximetry if the parents object. Tammy replied that there is a movement to respect parental choice. Dr. Betting doesn't feel parents should have the option to opt-out of the screening.

Early Hearing Detection and Intervention (EHDI)

Kim shared that ND EHDI is North Dakota's Early Hearing Detection and Intervention Program (EHDI) works to provide hearing screenings to all newborns in the state before hospital discharge and to refer those identified with a hearing loss to appropriate early intervention services.

It is important to note that ND EHDI is funded by two main grants, one through the Health Resources Services Administration (HRSA), and the other through the Centers for Disease Control (CDC), since ND EHDI currently receives no state funding. CSHS staff currently acts as a liaison between Department of Health programs/initiatives and ND EHDI

Currently, there is only one audiologist residing in western North Dakota (in Dickinson). Western North Dakota is experiencing an immense energy boom, which is bringing an influx of people to the western part of the state and an increase in births. Currently, Williston does not have an audiologist. In fact, the birthing hospital in Williston has discontinued providing outpatient hearing screening due to staff shortages seen with increased patient numbers. If an infant is discharged with a refer or missed hearing screen result, it is hopeful the infant receives an outpatient rescreen by an audiologist who commutes to the area on a weekly basis or is taken to Dickinson or Minot for follow-up services. Trinity has a new diagnostic ABR. This should reduce strain on pediatric diagnostics. Two audiologists from Minot will be traveling to Williston on 1st and 3rd Thursdays. One of them is trained to do ABR. Dr. Fiechtner asked if the funding was ongoing. Kim replied that EHDI has to reapply every three years. Dr. Fiechtner stated there are more audiologists coming to Dickinson. Lea stated there are two

audiologists in Dickinson. Dr. Carver asked who does the follow-up on most of the babies in Williston. Dr. Connell shared that Dr. Kemp sees many of the babies along with Dr. Jane Grorud and Dr. Lois Cook. Dr. Carver shared he does his own screens on the babies that fail the newborn hearing screening and he just walks the results across the hall to the audiologist. Kim shared that Dr. Carver is the only doctor in the state that has their own screener in their office. Kim shared that the Right Track program does have the capability to do the hearing screening, but it depends if children get referred or not and also the parents can choose not to have the Right Track visit.

CSHS Medical Eligibility

Transverse Myelitis (*Refer to draft policy on transverse myelitis.*)

Dr. Connell shared that a six-year-old girl was diagnosed with transverse myelitis at 18-months of age. The family applied for CSHS because she would like Botox treatment for some complications of her disease. CSHS enrolled her for treatment services under the condition of nerve injury. Transverse myelitis is not on the medical condition list. Dr. Connell shared her draft policy on transverse myelitis, which would make it a separate condition on the list. Dr. Carver motioned to include transverse myelitis on the medical condition list. Dr. Fiechtner seconded this motion. All were in favor. Motion carried.

Plagiocephaly

Dr. Connell shared there is an increase in plagiocephaly because of placing babies on their backs for sleeping. CSHS has not had an official request, but did have an inquiry. Should CSHS cover plagiocephaly? CSHS covers bony deformity and plagiocephaly would fit under that category. Dr. Fiechtner asked who would make the decision whether a child with plagiocephaly would need a helmet. Kim shared that the child would need an evaluation by an orthotist to determine the degree of severity. Should CSHS have a consultation with an orthotist be one of the criteria? Dr. Carver stated that there are some patients that he referred to an orthotist, because the parents insisted on it and the patient ended up with a helmet. Dr. Quanrud stated there should be some guidelines. Dr. Carver stated he believed there are guidelines by the AAP. Dr. Betting stated that Medicaid pays depending on severity. Dr. Quanrud stated that Gillette Children's Hospital has some good guidelines. Dr. Quanrud feels it is more important to treat the torticollis. Tammy replied that torticollis is on the medical condition list. Dr. Quanrud stated the medical condition list should be looked to update terminology. Dr. Connell stated that she would do some research on it and report to the council next year.

Fetal Alcohol Syndrome (*syndrome handout & Dr. Connell's slides*)

Dr. Connell shared that historically CSHS has covered chronic diseases that affect at least in part somatic issues. CSHS was recently asked if we would consider assisting with therapy services associated with some medical complications from fetal alcohol syndrome. CSHS met as group and evaluated the policy on syndromes (see handout). After much discussion, it was found that this particular child did have some medical conditions that would fall under our classification for "treatment of syndromes." With this type of scenario, should we look at covering Fetal Alcohol Syndrome from now on, or should we continue to evaluate on a case by case basis. Fetal alcohol syndrome does have some physical components to it. The neurodevelopmental diagnosis has some neurologic and developmental issues that might result in the need for physical therapy. Syndromes that are covered must meet CSHS criteria including chronicity, medical management, complexity, interventions, and seriousness. Dr. Carver asked what CSHS would cover. Dr. Connell shared that if the child has a condition that is on the medical condition list, CSHS typically covers the physical, occupational, and speech therapy. Dr. Carver stated that the disabilities CSHS would cover under this condition are the same as autism. Dr. Martsolf stated fetal alcohol spectrum disorder covers a bigger range than fetal alcohol syndrome. He also stated that fetal alcohol effect is a bad term and shouldn't be used. FAS is not a serviceable diagnosis in the schools unless they have other issues such as

ADHD. 60% of babies born to mothers with daily alcohol consumption do not have FAS. Dr. Quanrud would like to see a FAS waiver. The council doesn't feel FAS should be covered under syndromes. Rather CSHS can cover the eligible conditions a child might have as part of that syndrome.

Autism

Kim shared that CSHS has played a very active role in autism work in ND. Staff has been tracking and testifying on various legislative bills regarding autism this session, serve as a health representative on the Governor's Appointed Autism State Task Force, and are a partner in the Support Autism in ND (SAND) grant through Minot State University/North Dakota Center for Persons with Disabilities. Through the SAND grant, the Autism Resource Booklet (*handout*) has been updated using evidence based information and was reviewed by members of the AAP. It's available on the CSHS website. Tammy shared that there is some tension from various providers regarding what is evidenced based.

Financial Eligibility, Covered Services and Reimbursement Issues

Five-year Summary of Eligible Individuals Meeting \$20,000 limit

Kim gave a brief overview of the children who have met the \$20,000/year payment limit. In the last five years, there have been only two children who reached the limit. One child had cancer and maxed out in 2009. The other child had a cardiac condition and maxed out in 2011. CSHS was the child's only source of coverage. The child had surgery out of state including hospitalization and maxed out care for the remaining months of his financial review period possibly leaving them with a very costly bill for hospitalization and surgery. Staff worked with the local CSHS county worker to have them apply for Medicaid and possibly get retro authorization for out of state care to avoid maxing out CSHS coverage. The family did not follow through on the application. One child who has a seizure disorder has been a high cost, but has not reached the max yet. This child is covered under Caring for Children, but it does not cover medications. Thus, CSHS is acting as a gap filler, covering the medications. The Keppra runs \$1,300-\$1,400 per month. CSHS is following this closely but the financial review period ends in June so this family will likely slip right under the \$20,000 mark.

Review of Draft Coverage Policies

Kim shared that CSHS is currently paying for continuous glucose monitoring and insulin pumps under certain circumstances. To evaluate criteria for eligibility of these supplies, we have created two draft policies..

External insulin infusion pump:

This has been around for several years for Medicaid. Dr. Fiechtner asked how young the child is when he/she gets the pump. Dr. Connell said the youngest she has heard of was a three year old child. The policy states the child would have to have diabetes for six months before he/she could get a pump. Dr. Martsolf noted a spelling error in the first sentence of the draft policy. Dr. Quanrud motioned to accept the draft policy. Dr. Quisno seconded this motion. All were in favor. Motion carried.

Continuous glucose monitoring systems and insulin pumps:

Dr. Connell shared that this came up because Dr. Thurlow had a patient with hypoglycemic unawareness that really needs to chronically use the continuous glucose monitoring system so she doesn't have severe lows and end up having a seizure. Dr. Carver asked what the cost would be for the long-term use. Dr. Connell doesn't remember the actual cost, but said it was expensive. Dr. Quanrud motioned to accept the draft policy. Dr. Martsolf seconded this motion. All were in favor. Motion carried.

Gap-filling Services

Haberman bottles for babies with clefts:

Kim shared that typically, Medicaid allows six Haberman bottles/nipples for a child with a cleft lip/palate. There is currently no formal Medicaid policy in place regarding this issue. CSHS has encountered circumstances where the child's strong suck has required them to replace their Haberman much more frequently. The family tried different bottles but none worked. We did get them approved for 6 more nipples but that wasn't meeting their needs. This has resulted in CSHS needing to "gap fill," in order to prevent nutritional consequences for the infant. Numerous hours have also been spent on care coordination, meaning that CSHS staff has assisted the family by being a liaison between the family, Medicaid, Early Intervention/Family Subsidy, and CSHS. As the liaison, staff has assisted with achieving prior authorization for supplies, gathering relevant medical reports, and linking to local services. He was scheduled to have his palate repaired so hopefully he won't need the haberman bottles anymore. Dr. Quanrud asked if Kim called the company that makes the bottles. Kim replied yes, she did call the company, but they wouldn't sell the nipples separately.

Cochlear implant processors:

Kim shared that CSHS is providing coverage for an individual who is Medicaid (MA) eligible but does not meet their criteria for hearing aids. MA requires hearing loss averaging of 30 dB or greater in the ear with best hearing acuity for all recipients less than 21 years of age. CSHS only requires hearing loss of 20 dB or greater in one or both ears. We have needed to do some gap filling for MA eligibles. One inquiry was for a patient who needs a processor for her implant which was denied by Medicaid. Kim has not seen her application come through yet. Dr. Fiechtner recommended going to the company for help with the cochlear implant processors. Dr. Quanrud asked what MA's rule was for processors. Kim replied that she believes there is no rule. They are just not covered. Tammy stated that CSHS does try to be consistent with MA, but there are sometimes when CSHS does things differently. Dr. Fiechtner stated to also link families to Healthy Steps. Kim replied that every child that applies for CSHS is screened for Healthy Steps and MA. Dr. Quanrud stated that CSHS is using discretion appropriately when gap-filling.

Case Situations

Payment for extended diagnostic services without resulting eligible condition:

Kim shared that a child was seen by more than one pediatrician locally complaining of recurrent abdominal pain, episodes of vomiting, and headaches for the past two years. When the family applied with county social services, they were apparently told that CSHS would cover everything, not that it had to be linked to an eligible condition or ruling out an eligible condition. The family elected not to obtain health insurance. Local pediatricians found nothing abnormal as far as a gastrointestinal anomaly, celiac, inflammatory bowel, etc. One of the pediatricians finally referred to Dr. Blaufuss in Fargo for more extensive diagnostic testing, which again ruled out any CSHS eligible conditions. Dr. Blaufuss recommended a follow-up visit in two months. The first visit to Dr. Blaufuss was in August but CSHS did not receive the billing/reports until November. By the time CSHS reviewed the documentation and found no eligible condition, Dr. Blaufuss had seen the child again for a follow-up visit and did more testing, leaving the family with a large expense if CSHS did not cover. Since the county staff person was not able to confirm what was relayed to the family, CSHS decided to go back and cover those visits and tests even though there was really no eligible condition discovered, because the county is seen by the family as an extension of CSHS. We have not received reports from the follow-up visit that the family said they had in November. Kim asked the council if CSHS acted appropriately by covering the two visits. Dr. Quanrud asked why the county is an extension of CSHS. Kim explained that there is a CSHS worker in each county office that is responsible for accepting applications for CSHS. Dr. Quisno asked if the county worker has the authority to approve payment.

Kim replied that the county worker should not be telling the family what CSHS will pay for. Dr. Quanrud asked if the family was told before the first visit that CSHS would pay for the diagnostic visit and if everything was negative then this is all CSHS will cover. Kim replied that every family is sent a Family Handbook that clearly states that the diagnostic services are just for confirming and ruling out a condition. Dr. Quisno asked if the family was aggressive and if the county worker felt bullied. Dr. Connell stated that the family was very nice.

Botox coverage when insurance denied as experimental treatment for transverse myelitis

Dr. Connell shared that current CSHS policy based on past Medical Advisory Council advice states investigational/experimental treatment is not covered except when it's part of a formal process. CSHS recently received a claim for a Botox injection for transverse myelitis. Primary insurance denied this treatment as experimental. However, the CSHS medical director was able to find supporting documentation from Johns Hopkins, stating that this was appropriate treatment for the condition. How should we handle this? Dr. Quanrud stated that it's not experimental. Dr. Connell stated that it is approved for cerebral palsy, but not transverse myelitis.

Coverage of low-protein modified food products for glutaric acidemia

Dr. Connell shared that at last year's meeting there was discussion about talking with some legislators about what metabolic disease is and the fact that CSHS covers food and formula for MSUD and PKU, but does not cover it for other metabolic diseases, which is not comprehensive care for everyone. Kim shared that CSHS received an inquiry regarding payment of low-protein modified foods for a child with glutaric acidemia under the treatment program. Current treatment of this condition requires certain medications, specialized formula, and low-protein modified food. He is currently receiving his formula through WIC. Although this is a CSHS eligible condition, current CSHS policy regarding dietary covered services for metabolic disorders reads as follows: medical formula/foods, medically indicated coenzymes and food supplements, and genetic evaluation. Please note that current wording using "medical food" is meant to indicate specialized formula. This may need to be clarified as well.

N.D. Cent. Code § 26.1-36-09.7, § 54-52.1-04.11 - An insurance company, nonprofit health service corporation, or health maintenance organization must provide coverage for medically necessary medical foods and low-protein modified food products for the therapeutic treatment of an inherited metabolic disease. Coverage is not required in excess of \$3,000 a year total for low-protein modified food products or medical food for an individual with an inherited metabolic disease of amino acid or organic acid. Medical benefits coverage for low-protein modified food products or medical food is not required for an individual to the extent those benefits are available to that individual under a state department of health or department of human services program.

Kim stated that she could see a family trying to spin that and say that they should have their low-protein foods covered. The current law regarding the insurance mandate and needing to cover at least \$3,000 a year states that it can be for either medical food or low-protein modified food products. CSHS did inform the family that the answer was a no, because our policy states that CSHS only covers formula. Should CSHS consider covering low-protein modified foods for this child under the treatment program? Tammy shared that there is a difference in fairness. If a child has PKU or MSUD, the child can get what he/she needs without regard to income but if the child has another disorder that requires expensive formula, he/she has to be eligible at 185% of poverty. The formula and low-protein food are ordered differently. The formula can be ordered through a pharmacy. The low-protein food is ordered from special companies and the payment part is much more difficult. Right now for children with PKU, CSHS places the order for the family and it is very time intensive. Dr. Quisno asked if there could be a voucher system so a family could order their own food. Tammy replied it could be difficult to verify. There was an inquiry from a legislator about looking at increasing the age limit for men for PKU to 25. Diane shared that CSHS only pays for low-protein food for children that

are MA eligible. Dr. Carver asked what would be a special low-protein food. Diane shared that there are special breads, hot dogs, hamburgers, breakfast bars, pasta, and cheese. Dr. Quanrud asked how they could make a low-protein diet on regular food. Kim shared that they can have all the fruits and vegetables that they want. They can't have meat or milk. Laura Roberts asked if CSHS pays for children who have food allergies. Tammy stated no. Laura said it wouldn't be any different than having a child with food allergies. Dr. Carver stated that they are capable of obtaining the proper diet without the specialized foods. The council feels CSHS should be more conservative regarding low-protein food otherwise where does it end?

Coverage of INR labs

Kim shared that there was child who was required to have INRs done because of medication he is taking for his cardiac condition. Kim shared that current Cardiac Care for Children forms state that CSHS is able to cover "labs." We have found that this quite open-ended, since we have never specified which labs would or would not be covered under the Cardiac Program. The form has been changed now to state "select labs." Should CSHS cover labs under the Cardiac Care for Children program or should CSHS cover only certain labs under the program and then cover all over labs under the diagnostic program? With this particular case, CSHS decided that because the INR was being done as a result of his medication, which is treatment, they should then be covered under the treatment program. Specialists have given input and stated that typically ordered labs by the pediatric cardiologist include: INR, CBC, liver function, lipid profile, electrolytes, and iron. Tammy stated that the Cardiac Care for Children program has no income eligibility attached to it. CSHS wants the Cardiac Care for Children to have what it needs to operate effectively with the pediatric cardiologists who are doing the ongoing management for the children. Dr. Fiechtner asked if the program was entirely funded by CSHS. Tammy replied that the families' insurance is utilized as well. Dr. Connell shared that the asthma clinic is free. The child gets a free pulmonary function test, an evaluation by an asthma doctor, and education from some asthma educators. The family is responsible for paying for their medications, allergy evaluation, chest x-ray, or any other study. The children that attend the asthma clinic can apply for the treatment program and if they are income eligible, then CSHS will pay for their asthma medications, allergy evaluation, and testing relevant to their asthma. The difference between the asthma clinic and the Cardiac Care for Children program is that CSHS does not bill insurance for the asthma clinic. The Cardiac Care for Children program pays for chest x-rays, electrocardiograms, and echocardiograms which are very similar to the pulmonary function tests. The part that is different is the lab tests. Should the INR be included in the lab tests for the Cardiac program or should it be under treatment? CSHS feels fairly confident covering the CBC, liver function, lipid profile, electrolytes, and iron testing under the Cardiac program. Not every cardiac child needs the INR done. It's only the child that has undergone some treatment and the INR is a complication of the treatment. Dr. Quanrud feels the INR would go under the treatment program.

Programmatic Updates

Clinics

Kim shared that currently, the Fargo Sanford Craniofacial Clinic is being held approximately six times per year, generally the first Friday of even months. The clinic got off to a slow start, seeing only six children as of April 2013. The medical team consists of an ENT, craniofacial surgeon, and psychologist. The patients have been children with submucous clefts and one child with Treacher Collins syndrome. However, Children's Special Health Services is no longer concerned regarding the duplication of services in Fargo for children with cleft lip and palate. Dr. David Montes, the Sanford Craniofacial physician, is no longer seeing patients as of August 1, 2013. The coordinator for the Sanford Coordinated Treatment Center was unsure of the future of the clinic. CSHS was given instructions to refer families to the CSHS clinics. Dr. Quanrud asked if CSHS was looking at adding

Dr. Elliott to the cleft team in Fargo. Kim replied that there is an ENT on the team right now so at this time no. However, it would be nice to have a Sanford physician on the team. Dr. Martsolf asked if the family has to pay to attend the CSHS cleft clinics. Kim replied no.

New Contracted Services

Tammy shared that 16 proposals were submitted. There were 15 continuation requests, one new proposal, and one previously funded grantee that did not reapply. CSHS awards between \$500,000 and \$550,000 per biennium. However, with funding so uncertain at the federal level for the MCH Block Grant, staff may need to prioritize which projects are funded for the upcoming biennium. The contracted services currently support the multidisciplinary clinics, care coordination, medical home, and family support projects. Proposals have been reviewed independently by five separate reviewers and ranked using a point system.

CLOSING REMARKS/WRAP-UP

Five physicians have terms that will be expiring this year. They include Dr. Fiechtner, Dr. Feldman, Dr. Feil, Dr. Quanrud, and Dr. Kantak. Dr. Fiechtner would like Dr. Wink to take his place. Dr. Feil and Dr. Quanrud have agreed to another term. Dr. Feldman will be contacted to determine her interest. Dr. Connell would like to replace Dr. Kantak. Tammy stated a pediatric cardiologist would be nice to have on the council.

Dr. Connell closed the meeting after giving a warm thank you to the committee for all their hard work and support.